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Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies

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Abstract:**OBJECTIVE**

To review the qualitative and quantitative evidence of the benefits of peer support for parents of children with disabling conditions in the context of health, wellbeing, impact on family, economic and service implications.

METHODS

A comprehensive search of multiple databases was conducted. Eligible studies evaluated parent-to-parent support and reported on psychological health and experience of giving or receiving support. No limits on child's condition, study design, language, date or setting. We sought to aggregate quantitative data; findings of qualitative studies were combined using thematic analysis. Qualitative and quantitative data were brought together in a narrative synthesis.

RESULTS

Seventeen papers were included; nine qualitative studies, seven quantitative studies and one mixed methods. Four themes were identified from qualitative studies: (i) shared social identity, (ii) learning from the experiences of others, (iii) personal growth, and (iv) supporting others. Some quantitative studies reported a positive effect of peer support on psychological health and other outcomes, however this was not consistently confirmed. It was not possible to aggregate data across studies. No costing data were identified.

CONCLUSION

Qualitative studies strongly suggest that parents perceive benefit from peer support programmes, an effect seen across different types of support and conditions. However, quantitative studies provide inconsistent evidence of positive effects. Further research should explore whether this dissonance is substantive or an artefact of how outcomes have been measured.

What this paper adds

- Qualitative research consistently suggests that parent-to-parent support is beneficial across different types of support and conditions.
- Benefits from peer support for parents are less substantiated in quantitative research studies.
- It is unclear if the conflicting findings are because perceived benefits are not measureable or due to methodological issues such as insensitivity of the outcome measures used.

Parents of disabled children are at risk of chronic physical and psychological health problems, which appear to be both pervasive and likely to worsen over time.¹² Paediatricians in North America are encouraged to signpost parents towards family support programmes,³ and parents and carers in the UK are also encouraged to seek contact with relevant support groups.⁴⁵ The Department of Health in the UK is promoting an increased role for the voluntary, community and social enterprise sector in delivering health and social care.⁶ Integral to their vision is the need to examine, develop and strengthen the evidence base for social interventions such as parent support. The potential benefits of peer support have been evaluated in a broad range of groups, for example people with specific health conditions, such as cancer,⁷ mental health service users,⁸ people caring for others⁹ and for health promotions, such as breastfeeding.¹⁰ However we were unable to locate a systematic review evaluating the evidence of the effectiveness of peer support for parents of children with chronic disabling conditions. We perceived that it was reasonable to assume that any potential benefits of parent peer support were likely to be generic across children's long-term health conditions, rather than specific to any grouping of conditions.

The review sought to address the research questions (i) is peer support for parents of children with disabling conditions perceived as beneficial to their health, wellbeing and family functioning? (ii) are these effects measurable and long-lasting? (iii) what are the economic implications of this support, and how does it impact on service use and relationships with health care professionals?

This systematic review is part of a pilot programme evaluation of a one-to-one peer support service offered to parents by Face2Face,¹¹ a UK organisation that provides peer support for parents of children with disabling conditions.

Methods

SERVICE USER/PUBLIC INVOLVEMENT AND IMPACT

Involving patients, patients' representatives, other stakeholders and members of the public in research is believed to improve the utility of applied health service research; ¹² 'involvement' is strongly encouraged in the UK at present and mandatory for publicly funded research. Therefore it is important to record that the study questions addressed in the present study were developed in collaboration with a study-specific advisory group made up of three parents of disabled children from the PenCRU Family Faculty, four befrienders and the local coordinator from the Face2Face service who are also all parents of disabled children, representatives from relevant charities (Scope, Cerebra, Contact a Family, A Brighter Tomorrow), a local GP, two representatives from Devon County Council and one representative from the Council for Disabled Children. The group did not receive formal training for their involvement but were supported by members of the research team. Those who were not attending in a professional capacity received £ 25 per half day in acknowledgement of their time and contribution. Members of our advisory group were involved at key stages identified in a recent survey of involvement in systematic reviews: (i) in the suggestion of the topic and development of the research question; (ii) in the development of the protocol and specifically in determining the appropriate inclusion and exclusion criteria and identifying relevant outcomes; and (iii) in the conduct of the review by peer reviewing the completed draft of the paper. Members of the advisory group also co-authored a plain English version of the paper (supplementary material) for broader distribution of the findings to non-academic audiences, to be published on our research unit website and further disseminated via social networking and other opportunities.

SEARCH STRATEGY

A systematic search was conducted using multiple databases: MEDLINE (R) In-Process and Other Non-Indexed Citations and Ovid MEDLINE (R) 1948 to Present; Embase 1974 to 2011; PsycINFO; British Nursing Index and Archive 1985-2011; Health Management Information Consortium (HMIC)

1979-July 2011; The Cochrane Library (2011) including CDSR (Issue 7), CENTRAL (Issue 3), DARE (Issue 3), Methods Studies (Issue 3), Technology Assessments (Issue 3), Economic Evaluations (Issue 3); the Cumulative Index to Nursing and Allied Health Literature (CINAHL) 1981 to present; Social Science Citation Index 1980-2011. All databases were searched between the 29th June and the 5th July 2011. The searches were updated between the 24th and 27th February 2012.

The Medline search strategy (Table 1, adapted for other databases) was designed to include a number of search terms specific to parents and peer support, with the aim of capturing relevant data whilst minimising the vast amount of literature pertaining to 'support groups' in general. The overall search strategy therefore relied on covering a wide range of databases and subsequent citation chasing to identify all relevant studies.

We searched the online tables of content of key journals (Child: Care, Health and Development; Children's Health Care; Early Child Development and Care; Infants and Young Children; Journal of Pediatric Psychology; Pediatric Nursing), forward and backward citation searches of key authors and included papers. We sought grey literature through key websites: CanChild Centre for Childhood Disability Research (www.canchild.ca); Contact a Family (www.cafamily.org.uk); the Mentoring and Befriending Foundation, (www.mandbf.org); The Joseph Rowntree Foundation (www.jrf.org.uk); Social Policy Research Unit (www.york.ac.uk/spru); and OpenGrey, a system for information on grey literature in Europe (SIGLE 1980-2005) (www.opengrey.eu/).

STUDY SELECTION CRITERIA:

Consistent with the research question, studies were assessed for inclusion against the following criteria. The population was parents and caregivers of children with chronic disabling conditions including disabled, chronically or seriously ill children and young people. Studies pertaining to

bereaved parents, parents of babies in neonatal intensive care or parents of children receiving treatment for cancer were excluded.

Eligible interventions were informal or formal support offered to parents by parents in the form of one-to-one or group meetings. Internet or telephone support was excluded, as were professionally led or parenting skills training interventions. We did not exclude on the basis of comparator – hence studies comparing peer support with no peer support, those comparing between different types of support and those with no comparator group at all were eligible for inclusion.

The outcomes of interest were defined by member of our study stakeholder group. We included a broad range of outcomes; studies were eligible for inclusion if they reported on one or more of the following: psychological health of parents; experience of the person offering or receiving peer support; economic implications of peer support programmes; family functioning; accessing services and information; relationships with health professionals and long term impact of peer support.

Because of the small and disparate literature on parent peer support, we did not limit study inclusion by language, date, child's condition, setting or study design; although editorials, opinions, letters and reports published only as abstracts from conference proceedings were excluded.

Titles and abstracts retrieved by the electronic searches were screened by two reviewers (VS reviewed all articles retrieved, CM/JTC reviewed half each) using the inclusion/exclusion criteria. Disagreements were resolved by discussion with a third reviewer where necessary (CM or JTC). Full text copies of potentially relevant studies were obtained and assessed for inclusion using the criteria.

QUALITY APPRAISAL OF INCLUDED STUDIES

Qualitative papers were assessed using five appraisal prompts for informing judgements about the quality of the papers.¹⁴ Two reviewers (VS/CM) assessed each study independently, disagreements were resolved by discussion. Quantitative studies were assessed by one reviewer using a set of criteria developed using the principles published by the NHS Centre for Reviews and Dissemination and the Cochrane Collaboration. Scores were checked by a second reviewer.

DATA EXTRACTION AND SYNTHESIS

Quantitative data were extracted by one reviewer (VS) using a piloted, standardised form and checked by a second reviewer (CM). Where several studies used the same outcome measures, we contacted the authors for raw data from these studies in order to consider meta-analyses.

For qualitative studies, we extracted details of the methods of each study along with quotes, themes and concepts pertinent to our research questions. Data were extracted by two reviewers (VS/CM) independently and discrepancies resolved through discussion. The findings of each qualitative paper were coded and then grouped together into broad themes through discussion. The qualitative and quantitative data were then brought together in a narrative synthesis using tabulation and thematic analysis.¹⁵ We then sought to identify commonalities and differences between the qualitative findings and links between the quantitative and qualitative literatures.

Results

STUDY CHARACTERISTICS AND QUALITY APPRAISAL

Seventeen papers were included in the review (Figure 1), including seven randomised controlled trials, nine qualitative studies and one mixed methods evaluation (Table 2). Several studies evaluated peer support for parents of children with mixed conditions, others targeted parents of children with specific conditions including dyslexia, limb deficiency, diabetes. Details of the specific intervention under evaluation was lacking in some studies. Several studies were found to be lacking

in one or more areas of the quality of methodological design or completeness of reporting (Tables 3a and 3b). No studies were excluded on the basis of quality. We were, however, mindful of the limitations of individual studies, and the impact of these potential flaws, as the synthesis progressed.

Qualitative synthesis

Ten papers contributed data to the qualitative synthesis. Four themes were identified: (i) shared social identity, (ii) learning from the experience of others, (iii) personal growth, and (iv) supporting others. Four papers also identified when and why peer support does not work. (Table 4)

SOCIAL IDENTITY

The most common theme across studies related to benefits of finding a shared social identity with other parents; ¹⁶⁻²⁴ people not in a similar situation were considered not able to truly understand.^{18 22} ²⁴ The shared social identity fostered a sense of belonging, support and empowerment,¹⁹ enabled parents to feel better able to cope,²² and reduced senses of isolation, ^{18 20 23} loneliness and guilt.²³ It also provided a safe environment for support.^{20 21} The desire to seek out others with similar experience could be triggered at key times; for example during the process of obtaining a statement of educational needs, ¹⁷ or preparing for transition from paediatric to adult services.¹⁹ In some studies, the shared social identity led parents to meet outside the support programme, expanding their social and support network.^{21 23} For others, the sense of community and belonging gave parents the security to know that support was at hand if and when they needed it. ^{16 20 24} Conversely, this could result in a sense of loss if the security was removed, for example if a programme ceased to operate.²⁰

The need for a close match in parents' experiences was variably reported. An evaluation of one-to-one support suggested that the most successful matches occurred when parents perceived similarity not only in their children's situations, but also in parents' personalities and social backgrounds. ¹⁶

When parents perceived differences in the challenges faced by their children or in their own personalities and values, peer support was less successful.^{16 22} Not all studies, however, reported that close matching by diagnosis was necessary. Many issues are common to all families of disabled children and for some parents in group settings this was enough to form the identity.^{19 20}

LEARNING FROM THE EXPERIENCE OF OTHERS

The exchange of useful, practical information is an important element of support^{17 19 24 25} and many parents also described learning from the expertise and experience of other parents,^{16 19} through partnership and solving problems together.²⁰ Learning through social comparison and shared situations can be empowering¹⁹ and reassuring for less experienced parents and give them greater confidence in themselves²¹ and the future for their child.^{16 18 19 21} Mentors drew on their own experiences to help other parents gain confidence, or when offering reassurance and a positive outlook.²⁵

PERSONAL GROWTH

Several studies described how parents gained strength^{20 23} and were empowered^{16 20} through peer support which enabled them to develop new skills,²⁰ feel motivated,¹⁹ and affirm their expertise as parents.¹⁹ Other psychological benefits described included feeling more confident and in control,²³²⁴ less isolated,¹⁶ depressed and guilty.²³ In one study parents linked the changes in their own psychological health to becoming more accepting of themselves, which in turn had a positive impact on their relationship with their child.²³

SUPPORTING OTHERS

The benefits of peer support are not restricted to those receiving support. Parents in a number of studies report a sense of reciprocity and mutuality of support, that giving support was as important as receiving it.¹⁶ For some, being able to offer support to others was seen as part of an adaptive

process as they realised they needed less support themselves.¹⁸ Being able to support and share their experience validated their expertise as parents^{16 21} and increased their self worth.²¹ There was a strong motivation to offer the same support to other parents that they had benefitted from themselves.^{20 22 23} For some parents, mentoring others could bring back difficult memories such as their experiences at diagnosis, but this was typically described in a positive light, enabling them to see how far they had come in their own journey.²⁵

WHEN PEER SUPPORT DOES NOT WORK

Not all parents found peer support helpful, although none of the studies reported a harmful effect. Often a perceived lack of benefit was ascribed to inadequate shared social identity.¹⁶ Some parents found it difficult to divulge personal information to someone they perceived as a stranger,²² while others were disinclined to make contact because they were frightened of the comparison between their own and another child, which might be upsetting or painful to them or the other parent.²² A match between perceived need and what was received through peer support was important. For instance, in groups, parents with high levels of stress were less satisfied with the emotional support they received; the authors suggesting that these parents may benefit from individualised support.¹⁷ Parents who felt pressured by a professional to attend the group were less satisfied and did not intend to maintain regular attendance,¹⁷ underlining the differing needs and motivation of parents. Straightforward practicalities can also restrict success. Time is a particular concern for some parents who, with limited resources, prioritised the care of their child over time for themselves.^{19 22}

Quantitative synthesis

Eight studies contributed quantitative data which are tabulated by outcome assessed (Table 5). No quantitative studies investigated the costs of peer support, the experience of the person offering support, the impact of peer support on parents' relationships with health care professionals or the long term impact of peer support. Unless otherwise stated the means given in the table are

unadjusted. We have indicated in the final column whether analyses used adjusted or unadjusted scores. Studies did not report mean differences or 95% CIs, although we were able to calculate them for two papers.^{26 27} Although we secured some raw data for two studies it was not feasible or plausible to aggregate these data using meta-analysis. Many studies did not report p-values for all comparisons. P-values and mean difference in change scores have been provided in the text for all comparisons where p-values were reported and were ≤ 1 .

PSYCHOLOGICAL HEALTH

All studies reported outcomes of parent psychological health using a broad range of measures; see Table 5 for details of specific scales. Positive effects of peer support were reported in some studies for anxiety^{28 29} (mean difference in change score = -4.4, $p=.03$; mean difference in change score = -5.6, $p=.05$), concern³⁰ (mean difference in change score = -17, $p=.02$) confidence²⁶ (mean difference in change score = 8.1, $p=.02$) and coping³¹ (mean difference in change score = 0.26, $p<.012$ adjusting for multiple comparisons). Overall, however, there was no consistent evidence of effect on measures of anxiety,³² anger,^{29 32} cognitive disturbance,^{29 32} concern,^{26 27} confidence,^{27 30} coping,²² depression,^{28 29 32} empowerment,³¹ illness intrusion,²² overall mental health³² (mean difference in change scores = -4.7, $p=.08$)²⁹ and worry.^{26 27} One study reported a small effect on worry favouring the control group²⁶ (mean difference in change score = 9.9), $p = 0.1$, however the total sample was very small ($N = 28$).

Three studies suggest that peer support may impact differentially on certain subgroups of parents. Peer support appeared to be more beneficial to parents with higher numbers of stressful life events ($p<.05$),³² higher baseline anxiety ($p<.001$),²⁸ poorer baseline maternal health ($p<.001$),²⁸ or with lower baseline coping skills.³¹ However these subgroup findings should be interpreted cautiously.

FAMILY FUNCTION

Five studies reported on aspects of family function. One reported evidence of improvement with peer support on the validated 'Sources of Strength and Family Closeness' subscale – a measure of acceptance and family adjustment to disability (adjusted mean difference = 0.8, $p=.003$).³¹ Findings, however, showed little or no change with peer support on 'Impact on Family' scales: $p>0.1$ in three studies^{26 27 29} and $p=0.05$ in a fourth study (mean difference in change scores = -23)³⁰. No effect was found on father's involvement in the daily care of the child, although total sample size in this study was small (N=28).²⁶

THE EXPERIENCE OF PARENTS RECEIVING SUPPORT

Five papers reported the experience of parents receiving support. One reported that, in response to author developed questions, 89% of parents receiving peer support had found the support helpful. Parents that received peer support made more progress towards resolving the main problem that led them to join the study than the control group (adjusted mean difference = 0.49, $p=.003$, N=132).³¹ Four studies reported on perceived social support outside of the intervention.^{22 26 27 29} Only one reported evidence at the 5% level of a difference between groups and this measure was of absolute number of sources of support, rather than experience of the support received (N=42).²⁹

ACCESSING SERVICES AND INFORMATION

Only one study measured impact on accessing services and information. Weak evidence of an increase in the use of community resources by parents receiving peer support compared to the control group was observed ($p=.06$, mean difference in change score = 3) though the sample size was small (N=41).³⁰ No marked differences were seen in the number of emergency room or acute care visits or number of calls made to the specialist team (no data reported).³⁰

Discussion

The qualitative synthesis highlights important characteristics of peer support that appear to be generic across different types of support and medical conditions. These include the benefits of finding a shared social identity; the opportunity to learn practical information and also be inspired by others; going through a process of personal growth; and finally finding the ability to support others. The chronology to these stages of support is an overriding theme, thus an important feature of peer support would seem to be its potential for self-sustainability.

The qualitative findings are consistent with the growing awareness of the positive and 'protective' psychological and physical health effects of sharing a social identity with others;³³ and also the benefits derived by a person being able to offer support, known as the helper-therapy principle.^{34 35} However, quantitative studies did not substantiate these perceived benefits. Although the general trend on measures of psychological health favoured peer support, few studies reported strong evidence and, in the only study to measure it, no difference in the use of community or health care resources was observed.

The review was conducted using guidelines for narrative synthesis.¹⁵ The robustness of the synthesis may have been influenced by the study selection. The strict inclusion criteria led to us excluding a number of papers which, arguably, may provide insight into the organisational factors³⁶ and parent preferences^{37 38} that contribute to delivering a successful peer support service. These papers do not, however, report on outcomes of peer support consistent with the research question. Similarly, we chose not to include studies of peer support where the support was professionally led^{39 40} such as a support group led by a psychologist, which we consider to be fundamentally different to parent-led support which was the focus of the review. A further limitation relates to grey literature. We searched for grey literature using relevant websites we are familiar with in the UK, Canada and Europe. This returned no additional new papers, but we cannot be certain that a worldwide search of grey literature would have a similar outcome.

The methodological quality of the quantitative studies was largely acceptable, although limited by the small sample sizes. Also, the authors do not reflect on how much change in scores on the quantitative outcome measures they would have considered important, i.e. effect size, minimal detectable change, minimal important difference. These methodological issues may have influenced the individual study findings, notably the risk of a Type II error, whereby the quantitative studies failed to identify a positive impact of peer support on psychological health when in fact peer support is beneficial. In related studies, perceived social support has been shown to be strongly associated with the psychological health of parents of disabled children,^{41 42} and differences in the psychological health of parents receiving peer support in neonatal intensive care units have been reported.^{43 44} In many cases, the poor reporting of data limited what could be meaningfully included in the review tables; none of the studies reported both mean differences and 95% confidence intervals.

We had hoped to conduct meta-analyses to further strengthen the robustness of the review. Due to the age of some studies, however, authors were unable to provide raw data. Two groups of papers would have been appropriate to aggregate data. In neither group were we able to gain sufficient data to conduct meta-analyses. Sullivan-Bolyai and colleagues provided raw data from two papers,²⁶²⁷ but gathered data were from two populations (mothers and fathers) participating in the same study. We did not feel there was justification in aggregating this data although we were able to replicate the main findings reported in the papers.

We did not consider any of the qualitative studies to be “fatally flawed”,¹⁴ but the variable quality of reporting and depth of analysis led us to consider some studies to be of poorer quality than others. We found a high level of agreement between studies in the thematic analysis and we do not consider that studies with poorer reporting quality affected the overall shape of the synthesis. We

did not differentiate between one-to-one and group support in the thematic analysis because we found the emerging themes to be consistent across both forms of support.

Overall it was not possible to fully answer the review questions. None of the studies included an evaluation of cost-effectiveness or any details regarding financial costs. Very few studies interviewed parents who had had a negative experience of support hence this perspective is underreported. This is an artefact of the type of study whereby those actively engaged in a support service are likely to have a positive view of it; this, however, places limitations on the implications that can be drawn from the review.

Several further design considerations influenced the interpretation of study findings. Peer support interventions included in the review varied in the quantity and content of parent interactions, the duration of the intervention, and whether or not the supporting parents were trained. Typically the interventions delivered as part of a trial were more tightly defined than in observational studies. It is unclear to what extent any manipulations for the purpose of research may change the nature of a complex intervention such as peer support.⁴⁵ We cannot comment on the impact of these factors on individual study findings. The variability across studies does, however, limit the inferences we can make.

We purposefully included studies involving parents with children who had a broad range of chronic health problems not just neurodevelopmental conditions, consistent with a non-categorical approach to the parents' situations. Some may consider that parents of children with different medical conditions, or varying severity, might have differing reactions and needs for support. This may well be the case. Nevertheless, members of our advisory group felt that this was not their experience, and Face2Face does counsel parents of children with any condition.

Linked but quite distinct to the *length* of intervention is *exposure* to intervention. It is likely that parents interact with support to a degree that they perceive they need it. Hence some families may feel that they do not need or want support.²² Mothers who chose not to be randomised reported fewer psychological symptoms and perceived more social support than those who were randomised²⁹ which the authors speculate was because they perceived little need for additional support. Two studies investigated the potential of a dose-response relationship and found no evidence of such an effect.^{28 32} Parents' engagement in 'real world' support is determined by their own needs and capacity rather than receiving a 'prescribed dose'. Studies also varied as to whether parents were matched based on the child's diagnosis. Matching by diagnosis was reported as important in some studies^{16 22} but not all.^{19 20} Whether the support being offered is one-to-one or group may impact the importance of matching by diagnosis and is an area for further investigation as matching was not explored explicitly in all studies.

Systematic and explicit investigation of participants' use of other forms of peer support is required. One study that reported significant positive effects of a one-to-one intervention acknowledged that all mothers in the intervention group were also involved in a parent support group outside of the intervention, when only a few mothers in the control group were similarly involved.³⁰ This was not controlled for in the analysis and it is therefore not possible to identify the specific effect of the intervention. By contrast, another study specifically excluded parents as participants if they were already participating in a Parent-to-Parent support programme or were attending a support group.³¹ This raises both methodological and ethical considerations around how to control for different forms of support that parents may access while participating in a pragmatic trial.

A number of methodological challenges for investigating peer support have been identified which should be addressed in future research. First, what measures of health outcomes are theoretically appropriate, and plausibly consistent with what should be expected as proximal to the effects of

peer support as an intervention? Second, is there evidence to support the responsiveness of the selected outcome measure scale to be able to detect important health change in this context? Third, what timeframes are appropriate, both in terms of the duration of peer support as an intervention and time elapsed before follow-up assessment of outcome? Finally, what is appropriate to use as a control comparator in this context, i.e. is it appropriate to ask parents to wait for support, and how and if it is ethical or necessary in a pragmatic trial to prevent parents from seeking other types of support in addition to the study's own intervention?

This review has identified the need for more robust evaluation of peer support services and identified several methodological challenges. More rigorous evaluation is necessary to help both parents and service commissioners make informed decisions about the potential benefits and costs of peer support services.

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References

1. Brehaut JC, Garner RE, Miller AR, Lach LM, Klassen AF, Rosenbaum PL, et al. Changes over time in the health of caregivers of children with health problems: growth-curve findings from a 10-year Canadian population-based study. *Am J Public Health* 2011;101(12):2308-16.
2. Brehaut JC, Kohen DE, Garner RE, Miller AR, Lach LM, Klassen AF, et al. Health among caregivers of children with health problems: findings from a Canadian population-based study. *Am J Public Health* 2009;99(7):1254-62.
3. The pediatrician's role in family support and family support programs. *Pediatrics* 2011;128(6):e1680-4.
4. HM Government. Support groups for parents of disabled children. http://www.direct.gov.uk/en/CaringForSomeone/CaringForADisabledChild/DG_10026501. Last accessed 01/08/2012.
5. NHS Choices. Parent support groups. . <http://www.nhs.uk/carersdirect/guide/parent-carers/pages/parentsupportgroups.aspx>. Last accessed 01/08/2012.
6. Department of Health. Social action for health and well-being: Building co-operative communities. Department of Health strategic vision for volunteering. . www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_130503. Last accessed 01/08/2012.
7. Hoey LM, Ieropoli SC, White VM, Jefford M. Systematic review of peer-support programs for people with cancer. *Patient Educ Couns* 2008;70(3):315-37.
8. Repper J, Carter T. A review of the literature on peer support in mental health services. *J Ment Health* 2011;20(4):392-411.
9. Charlesworth G, Shepstone L, Wilson E, Reynolds S, Mugford M, Price D, et al. Befriending carers of people with dementia: randomised controlled trial. *BMJ* 2008;336(7656):1295-7.
10. Jolly K, Ingram L, Khan KS, Deeks JJ, Freemantle N, MacArthur C. Systematic review of peer support for breastfeeding continuation: metaregression analysis of the effect of setting, intensity, and timing. *BMJ* 2012;344:d8287.
11. Scope. Face 2 Face – the one-to-one befriending service for parents of disabled children. <http://www.scope.org.uk/face2face>. Last accessed 01/08/2012.
12. Staley K. Exploring impact: public involvement in NHS, public health and social care research. Eastleigh: INVOLVE, 2009.
13. Kreis J, Puhan MA, Schunemann HJ, Dickersin K. Consumer involvement in systematic reviews of comparative effectiveness research. *Health Expect* 2012.
14. Dixon-Woods M, Cavers D, Agarwal S, Annandale E, Arthur A, Harvey J, et al. Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Med Res Methodol* 2006;6:35.
15. Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, et al. Guidance on the conduct of narrative synthesis in systematic reviews. Final report, Institute of Health Research, Lancaster: ESRC Methods Programme., 2006.
16. Ainbinder JG, Blanchard LW, Singer GHS, Sullivan ME, Powers LK, Marquis JG, et al. A qualitative study of parent to parent support for parents of children with special needs. *Journal of Pediatric Psychology* 1998;23(2):99-109.
17. Bull L. The use of support groups by parents of children with dyslexia. *Early Child Development and Care* 2003;173(2-3):341-47.
18. Kerr SM, McIntosh JB. Coping when a child has a disability: exploring the impact of parent-to-parent support. *Child Care Health Dev.* 2000;26(4):309-21.
19. Kingsnorth S, Gall C, Beayni S, Rigby P. Parents as transition experts? Qualitative findings from a pilot parent-led peer support group. *Child Care Health Dev* 2011;37(6):833-40.

20. Law M, King S, Stewart D, King G. The perceived effects of parent-led support groups for parents of children with disabilities. *Physical and Occupational Therapy in Pediatrics* 2001;21(2-3):29-48.
21. Lo L. Perceived benefits experienced in support groups for Chinese families of children with disabilities. *Early Child Development and Care* 2010;180(3):405-15.
22. Nicholas DB, Keilty K. An evaluation of dyadic peer support for caregiving parents of children with chronic lung disease requiring technology assistance. *Social Work in Health Care* 2007;44(3):245-59.
23. Solomon M, Pistrang N, Barker C. The benefits of mutual support groups for parents of children with disabilities. *American Journal of Community Psychology* 2001;29(1):113-32.
24. Rearick EM, Sullivan-Bolyai S, Bova C, Knafl KA. Parents of Children Newly Diagnosed With Type 1 Diabetes Experiences With Social Support and Family Management. *Diabetes Educator* 2011;37(4):508-18.
25. Sullivan-Bolyai S, Lee MM. Parent mentor perspectives on providing social support to empower parents. *Diabetes Educ* 2011;37(1):35-43.
26. Sullivan-Bolyai S, Bova C, Lee M, Gruppuso PA. Mentoring fathers of children newly diagnosed with T1DM. *MCN Am J Matern Child Nurs* 2011;36(4):224-31.
27. Sullivan-Bolyai S, Bova C, Leung K, Trudeau A, Lee M, Gruppuso P. Social Support to Empower Parents (STEP): an intervention for parents of young children newly diagnosed with type 1 diabetes. *Diabetes Educ* 2010;36(1):88-97.
28. Ireys HT, Chernoff R, DeVet KA, Kim Y. Maternal outcomes of a randomized controlled trial of a community-based support program for families of children with chronic illnesses. *Arch Pediatr Adolesc Med* 2001;155(7):771-7.
29. Ireys HT, Sills EM, Kolodner KB, Walsh BB. A social support intervention for parents of children with juvenile rheumatoid arthritis: results of a randomized trial. *Journal of Pediatric Psychology*, 1996:633-41.
30. Sullivan-Bolyai S, Grey M, Deatrick J, Gruppuso P, Giraitis P, Tamborlane W. Helping other mothers effectively work at raising young children with type 1 diabetes. *Diabetes Educ* 2004;30(3):476-84.
31. Singer GHS, Marquis J, Powers LK, Blanchard L, Divenere N, Santelli B, et al. A multi-site evaluation of Parent to Parent programs for parents of children with disabilities. *J. Early Interv.* 1999;22(3):217-29.
32. Silver EJ, Ireys HT, Bauman LJ, Stein REK. Psychological outcomes of a support intervention in mothers of children with ongoing health conditions: The parent-to-parent network. *Journal of Community Psychology* 1997;25(3):249-64.
33. Haslam SA, Jetten J, Postmes T, Haslam C. Social Identity, Health and Well-Being: An Emerging Agenda for Applied Psychology. *Appl Psychol-Int Rev* 2009;58(1):1-23.
34. Solomon P. Peer support/peer provided services underlying processes, benefits, and critical ingredients. *Psychiatr Rehabil J* 2004;27(4):392-401.
35. Salzer MS, Shear SL. Identifying consumer-provider benefits in evaluations of consumer-delivered services. *Psychiatr Rehabil J* 2002;25(3):281-88.
36. King G, Stewart D, King S, Law M. Organizational characteristics and issues affecting the longevity of self-help groups for parents of children with special needs. *Qualitative Health Research* 2000;10(2):225-41.
37. Santelli B, Turnbull A, Sergeant J, Lerner EP, Marquis JG. Parent to parent programs: Parent preferences for supports. *Infants Young Child.* 1996;9(1):53-62.
38. Santelli B, Turnbull AP, Marquis JG, Lerner EP. Parent to parent programs: a unique form of mutual support. *Infants & Young Children: An Interdisciplinary Journal of Special Care Practices* 1995;8(2):48-57.
39. Smith K, Gabard D, Dale D, Drucker A. Parental opinions about attending parent support groups. *Children's Health Care* 1994;23(2):127-36.

40. Shapiro J. Stress, depression, and support group participation in mothers of developmentally delayed children. *Family Relations: An Interdisciplinary Journal of Applied Family Studies* 1989;38(2):169-73.
41. Raina P, O'Donnell M, Rosenbaum P, Brehaut J, Walter SD, Russell D, et al. The health and well-being of caregivers of children with cerebral palsy. *Pediatrics* 2005;115(6):e626-36.
42. Manuel J, Naughton MJ, Balkrishnan R, Paterson Smith B, Koman LA. Stress and adaptation in mothers of children with cerebral palsy. *J Pediatr Psychol* 2003;28(3):197-201.
43. Preyde M, Ardal F. Effectiveness of a parent "buddy" program for mothers of very preterm infants in a neonatal intensive care unit. *Can. Med. Assoc. J.* 2003;168(8):969-73.
44. Roman LA, Lindsay JK, Boger RP, DeWys M, Beaumont EJ, Jones AS, et al. Parent-to-parent support initiated in the neonatal intensive care unit. *Research in Nursing & Health* 1995;18(5):385-94.
45. Doull M, O'Connor A, Welch V, Tugwell P, Wells G. Peer support strategies for improving the health and well-being of individuals with chronic diseases. *Cochrane Protocol* 2008.